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ABSTRACT

This monograph represents the collective thinking of parents of children with special health needs, family members, and professionals concerning what is necessary and important in collaborative relationships. Collaboration is viewed as a way to improve quality of life and health of children and their families, by working together to humanize the service delivery system in a spirit of shared ownership and responsibility. Seven principles of family/professional collaboration are discussed. Family/professional collaboration: (1) promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family; (2) recognizes and respects the knowledge, skills, and experience that families and professionals bring to the relationship; (3) acknowledges that the development of trust is an integral part of a collaborative relationship; (4) facilitates open communication so that families and professionals feel free to express themselves; (5) creates an atmosphere in which cultural traditions, values, and diversity of families are honored; (6) recognizes that negotiation is essential in a collaborative relationship; and (7) brings to the relationship the mutual commitment of families, professionals, and communities. The monograph concludes with a list of people and programs involved in the University of Vermont's Family/Professional Collaboration Project and a list of key elements of family-centered care. (Contains 39 references.) (JDD)

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ED 381 518

Family/Professional Collaboration

for Children with Special Health Needs and Their Families

Kathleen Kirk Bishop, D.S.W.
with
Josie Wolf
and
Polly Arango

DEPARTMENT OF SOCIAL WORK
THE UNIVERSITY OF VERMONT
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We would like to extend our appreciation to Merle McPherson, M.D., Director, Division of Services for Children with Special Health Needs, for her enthusiasm, support and commitment to the principles and practice of Family/Professional Collaboration.

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For more information, please contact:

Kathleen Kirk Bishop, D.S.W., Project Director
Peggy Weaver, M.S.W., Project Coordinator
Karen Witkin, Parent Coordinator
Mary Ann Gaschnig, M.S.W., Research Coordinator
Family/Professional Collaboration Project
Department of Social Work
University of Vermont
499B Waterman Building
Burlington, Vermont 05405-0160
(802) 656-8800

Family/Professional Collaboration for Children with Special Health Needs and Their Families

Kathleen Kirk Bishop, D.S.W.
with
Josie Woll
and
Polly Arango
in collaboration with
Families and Professionals

Family/Professional Collaboration for Children with Special Health Needs and Their Families

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Dedication

We who have children with special health needs acknowledge the challenging gifts that our children have given us. They have taught us that patience, persistence, and joy should infuse every aspect of our lives. In turn, we have been enriched immeasurably as we have woven those lessons into our interactions within our own families and with all the professionals who share our devotion to our children, and our commitment to collaborating on their behalf.

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Acknowledgements

This monograph celebrates more than ten years of dialogue with the many parents, family members, and professionals who have willingly engaged with us in endless conversation and debate—sometimes in formal meetings, but more often in hotel rooms, in offices, on airplanes, in taxicabs, in their homes and ours, on long drives and in snowstorms.

This monograph was created with the enthusiastic support and commitment of **Merle McPherson, M.D.,** Director, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau. Merle believed in and supported family/professional collaboration long before it was fashionable to do so. She has modelled over the years the many principles contained in this monograph. Merle has been and continues to be a true partner in family/professional collaboration.

Many people contributed to this monograph.

Our National Advisory Board Members, **Betsy Anderson, Polly Arango, Nancy DiVenere, Isadora Hare, Carol Hassler, Barbara Steele, Joan Weiss,** and **Josie Woll**, worked through several days of meetings over the last two years, sharing their ideas and experiences, commenting on drafts, willingly engaging in telephone debates, and believing in the importance of this work.

Our Focus Group Members, **Cathy Crow, Nancy DiVenere, Carol Hassler, Cindy Hayman, Michele O'Neill, Susan Rump, Carlos Santiago, Evelyn Sikorski, Megan Sutton,** and **Janet Vohs,** participated through meetings, telephone conversations, and in giving written comments on definitions and descriptions of collaboration, all of which helped to shape a series of ideas into what are now the Principles of Family/Professional Collaboration.

The Family/Professional Collaboration Project Staff played numerous roles in seeing this monograph through to completion with unwavering energy and commitment. **Anne Wallace**, former staff member, worked on some of the beginning ideas, organization, and structure of the monograph. **Karen Witkin,** Parent Coordinator, contributed her thoughts and experiences as a parent to the monograph. **Peggy Weaver**, Project Coordinator, collected, organized, and integrated the Practice Examples. Anne, Karen, and Peggy also engaged in endless debates and work on words and their meanings, and how best to communicate the principles of collaboration. And, **Pauline Chicoine**, our Project Secretary, typed and re-typed many drafts and attended to unending details with incredible patience and a quiet steadiness.

Many, many families and professionals responded to our early call to State Health Departments, Parent Groups, Special Projects of Regional and National Significance, and others for **Best Practice Examples**. We received many examples from all of you, demonstrating that Family/Professional Collaboration is indeed alive and well. We used as many suggested programs as we could, but all of the submissions shaped and influenced the thinking expressed in the monograph.

The ideas for this monograph also come from the work and publications of several groups—the **Federation for Children with Special Needs** (Boston), the **Families as Allies Project** (Oregon), the **Association for the Care of Children's Health** (Washington, D.C.), and **Parents Groups** throughout the country. Many other groups, too numerous to mention, have influenced our thinking about collaboration.

To all of you, we acknowledge your contribution and thank you for your encouragement and support.

There is no limit to the creative potential a collaborative relationship has to offer. We all have experienced it. We hope this monograph will help others to develop and experience great collaborative relationships.

Kathleen Kirk Bishop
Josie Woll
Polly Arango

From the Director...

In 1989, amendments were enacted to the Title V MCH Grant (MCH Block Grant). These amendments defined a national agenda for children with special health needs and their families based on new social policy. Why such a broad national movement? Simply stated, data and statistics tell us that children and families are disproportionately at risk. The litany of economic and social ills and assaults on families' ability to lead healthy, productive lives is increasing; conversely, permanent, stable services and supports needed by families are increasingly fragmented or not available. There is a common agenda to rebuild not just the economic infrastructure in this country but also the human services infrastructure for the delivery of health, education, social, and a variety of other services for children and their families.

I came to the Federal bureau in 1977 and had the privilege of engaging in a national consensus process which involved an exciting array of families and professionals. From those many studies, reports, conferences, workshops, and individual conversations, a new paradigm has emerged. We have recognized the critical role of families in their children's lives and have learned to see ourselves as service and support personnel. The paradigm shift requires new ways of working between families and the many agencies, professionals, and others who interact with and influence their lives.

Kathy Bishop, one of the authors of this monograph, was also on the staff of the Bureau and she is the person most responsible for reshaping Bureau policy to a family-centered philosophy and for insisting that family/professsional collaboration was the critical focus needed to change program and practice. She has pursued that professional interest at the University of Vermont, and, with an outstanding group of collaborators, has produced this monograph.

Polly Arango and Josie Woll, the parent authors of this monograph, have been leaders in modelling family/professional collaboration for all of us in numerous ways at the federal, state and local levels. They, along with many other family members in this country, continue to be partners with us in working toward the best medical and health services for children with special health needs and their families.

The monograph dares to go beyond the rhetoric to frame a set of Principles which will influence policy and programs and practices for all of us concerned with the health of children and families. We encourage you to use and share this valuable resource as we seek to learn new roles and responsibilities for families and for professionals.

Merle McPherson, M.D., Director
Division of Services for Children with Special Health Needs
Maternal and Child Health Bureau
U.S. Department of Health and Human Services

Preface

This monograph represents the collective thinking of many parents, family members, and professionals as it developed from a series of meetings and discussions, formal and informal, which were begun in 1984 at the Division of Services for Children with Special Health Needs at the Maternal and Child Health Bureau.* It is a continuation of the family-centered philosophy which is contained in the history of Maternal and Child Health.

The principles of family/professional collaboration include the behaviors, beliefs, attitudes, and values that must be present in a collaborative relationship. These principles are more descriptive than definitive. They may not be all inclusive, but we have attempted to translate what families and professionals around the country have told us is necessary and important in collaborative relationships.

As we reviewed the literature—formal and informal works, books, journal articles newletters, correspondence, meeting notes, speeches— we were struck by how professionals needed to work differently with families in order to allow collaboration to happen. This call for change within the professional role was distributed fairly evenly across the parent/family and professional literature. What seemed to be missing, from the professional perspective, was what effect(s) collaboration might have on professionals within the context of their own professions, agencies, and organizations. Are professionals giving up anything? Then too, there is very little examination of the family role in collaboration. Is something different required of families? Are families being asked to do more? As we strive toward more collaborative ways of working together, what will be the cumulative and interdependent effects on families and professionals—and how do we prepare families and professionals for these new expectations? These are questions that we need to continue to explore.

This monograph represents a conscious struggle with language and ideas to represent the shift in thinking required to collaborate. We experienced that shift and struggle firsthand. In no way do we believe these words represent the final description of collaboration, but we hope it is a good beginning.

*Formerly named the Habilitative Services Branch, Office of Maternal and Child Health, U.S. Department of Health and Human Services

Introduction

Collaboration is about children and families. It is for children, family members and professionals. We are working to develop collaboration because we want to improve the quality of life and the health of children and their families.

> *The reason I want to collaborate is because I want something for my daughter that otherwise would simply not happen. There's no way I'm going to be able to accomplish for her the kind of future she wants for herself and that I want for her without some really powerful partners.*
>
> *(J. Vohs, Parent)**

Collaboration is about how to do it together. It makes sense to work together. It is respectful. Families and professionals have said that it is important, that they experience greater satisfaction, that it advances the services for children with special health needs.

> *It [collaboration] gets back to that child. A child with special health care needs is often more complex than a typical child. Therefore the need for collaboration and maybe complicated kinds of collaboration is paramount. It is critical. I think we always need to come back to the child, making sure that he or she has the kind of care that he or she needs. You can't expect that one person is able to give the kind of care that a child with complex medical challenges needs. Collaboration on behalf of a child with special health care needs requires a complex configuration of care-giving.*
>
> *(P. Arango, Parent)*

Collaboration is a way to humanize the service delivery system. It improves the outcomes for children with special health needs and their families. Collaboration facilitates satisfying and effective relationships.

> *I was thinking of why we should collaborate—one being that the whole is greater than the sum of its parts, that there's something above and beyond the individual pieces. I was thinking of the energy and reinforcement that goes along with collaboration. This is hard work! With collaboration you get reinforcement, which certainly does give one satisfaction. It's really fabulous when you get to a point where it's more than what you ever expected.*
>
> *(B. Anderson, Parent)*

*For more information about any of the people quoted, programs and practice examples, consult People and Programs and Readings and References.

Collaboration is a way of thinking and relating, a philosophy, a paradigm shift, an attitude change. It requires a set of behaviors, beliefs, attitudes, and values. The result is a sense of shared ownership, shared responsibility, shared success. No one can do it alone. Improving the quality of life and the health of children with special health needs and their families requires the collective knowledge, skills, experience, and expertise of all family members and professionals. It requires that the community and all service systems work together to achieve the goals of the child and family.

> *I work collaboratively with families not only because it's the right way to do things, but because it's the most enjoyable, energizing and satisfying way to provide services.*
> *(A. Wallace, Professional)*

Collaboration is not easy. It is hard work. It requires receptiveness and openness. It takes time and energy. It requires commitment. It means you are willing to change.

> *I have always been able to collaborate with the professionals involved in my sons' care but not without effort. It never came easy. Professionals were sometimes hesitant because they didn't know how involved I wanted to be, as one physical therapist told me. I asked questions. I walked on into that therapy session. I had to make that effort to communicate and become involved. When there were disagreements, I stood firm on decisions proven best for my sons and, most of the time, convinced the professionals. The respect won through this process for both parties has resulted in a very strong partnership for Shawn and Jason.*
> *(K. Pounds, Parent)*

Collaboration involves parent and professional, professional and child, parent and parent, professional and professional, agency and parent, federal and state administrators, and others. Collaboration will not look the same for all families and professionals. Some collaborative relationships will be simple to develop, others will be much more complex and demanding. Collaboration must be developed between and among all of us.

Principles of Family/Professional Collaboration

Family/professional collaboration:

1. promotes a relationship in which family members and professionals work together to ensure the best services for the child and the family;

2. recognizes and respects the knowledge, skills and experience that families and professionals bring to the relationship;

3. acknowledges that the development of trust is an integral part of a collaborative relationship;

4. facilitates open communication so that families and professionals feel free to express themselves;

5. creates an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored;

6. recognizes that negotiation is essential in a collaborative relationship; and

7. brings to the relationship the mutual commitment of families, professionals, and communities to meet the needs of children with special health needs and their families.

Family/Professional Collaboration Promotes a Relationship in Which Family Members and Professionals Work Together to Ensure the Best Services for the Child and the Family.

PRINCIPLE 1

In order to ensure the best services for the child and family, families and professionals need to develop a relationship within which they can work together. This working together aspect of the relationship cannot be taken for granted, but must be intentionally and carefully built and nurtured by professionals and families alike.

Collaborative relationships might be compared to team building. A team develops through time spent together—learning each other's strengths and abilities, learning when to give and when to stand back. If we are able to develop a strong team committed to working on behalf of my child and family, I believe we will experience better outcomes.
(K. Witkin, Parent)

The notion of working together may seem too obvious to elaborate upon; yet, too often, when the families of children with special health needs seek services and become involved in relationships with providers, they become the recipients of the services, rather than partners in the design, implementation, and evaluation of the services. If families and professionals are striving to work collaboratively, no longer can professionals do something to families. We must be engaged as partners.

Our attitudes really make a difference in our relationships. As professionals, we must relate to parents as equal partners, and we have to be comfortable in our role as consultants to the parents, recognizing that they are ultimately responsible for making the major decisions regarding the care of their children. It is important to respect each other, including our differences, and recognize each other's values. We must have compassion for each other as well as the children.
(S. Handmaker, Professional)

When family members and professionals work together to develop and ensure the best services for children and families, they demonstrate a shift in philosophy, a new way of relating to each other. They become partners, sharing the responsibility, the fears, the joy, the satisfaction that comes from working in partnership. Does anyone give up power and control? Perhaps! Does anyone compromise? Perhaps! But does the bottom line, doing what makes sense for the child and family, ever change? No. As long as everyone involved—child, family, professionals—understands and shares that common goal, then the flexibility and liquidity critical to any relationship can work its magic.

How do such relationships develop? We believe that, even in the context of a traditional system of health care, opportunities arise for parents and professionals to interact in ways that, slowly perhaps, interrupt old patterns, connect with new ideas, and communicate a mutuality of interest.
(C. Hassler, Professional, and N. DiVenere, Parent)

Families who have children with special health needs engage in many relationships with professionals over a long period of time. Therefore, it is important for administrators and supervisors to understand that the development of a collaborative relationship takes time and may appear to be less efficient in the short run. Working together initially may consume considerable time and energy as the elements of collaboration, such as developing trust and demonstrating a respect for cultural traditions, are worked out. In the long run, however, energy and dollars invested in collaborative relationships will not only contribute to ensuring the best services for children and families, but will also support the work of the professional partner.

Our kids are not very likely to be cured, so we really want long-term, productive relationships.
(B. Anderson, Parent)

PRACTICE EXAMPLES

FAMILY

When we brought Elsie home from the hospital, there were ongoing issues of concern. One of these issues had to do with her nutrition and the balance of some basic elements in her body. When I asked my pediatrician about it, he said: "I'm not sure what I'm looking for; who should I call to find out?" It was wonderful. I referred him to one of her physicians from the hospital and I was all set. He didn't question the issue I raised and he was honest in response. I felt like we were working with Elsie together. (Megan Sutton, Parent to Parent of Vermont, Middlebury, Vermont, 802 545-2475)

COMMUNITY

Un Buen Comienzo/A Good Beginning (UBC) offers daycare and therapeutic services to young children with special needs and their families. This program is part of the Rosemount Center, a bilingual and multicultural daycare which encourages peer interaction and socialization among all children of various ages ranging from four weeks through five years. The developmental curriculum is enriched by the intertwining of multicultural and bilingual components. In our view, partnerships with team members involved in program planning for children enrolled in our program are as important as the work accomplished through the services we provide; of course the family is placed at the head of this team when it comes to decision-making and advocacy issues. We always assume that the family knows what is best for their child and will advocate for him/her in all situations. Many Hispanic families in our program have recently immigrated to the United States and are not fluent in English.

We have found that these families often want the UBC staff to take a lead role initially in creating the child's program plan. As team leaders we then adopt the role of advocate for the family and help empower them to become advocates for their children. (Isabella Lorenzo-Hubert, M.Ed., and Laura Vaughan, M.Ed., CCC-SLP, Un Buen Comienzo Program, Rosemount Center, Washington, D.C., 202 265-9885)

STATE PROGRAM

In the State of Florida, in order to develop training that will focus on collaboration, communication, and growth, for both Children's Medical Services (CMS) staff and Florida families, CMS has created a state parent consultant position. This parent will assist our 20 statewide district CMS offices in designing a more sensitive system of delivery including "family rooms" not "waiting rooms," information bulletin boards, family library, etc. (Michele S. Kern, R.N., Program Administrator, Children's Medical Services, Tallahassee, Florida, 904 488-5040)

NATIONAL PROGRAM

The Alliance of Genetic Support Groups is a coalition of consumers, professionals, and voluntary genetic support groups, developed so that families and health care professionals can work together to address the needs of individuals and families affected by genetic disorders from a national and cross disability perspective. The Alliance believes that the beginning of a true working relationship, the essence of partnership, can be realized through the full integration of consumers into the regional Genetics Networks. These networks work to improve access to and quality of genetic services. They identify needs, share resources, and enhance communication and coordination among states within each region. (Jayne Mackta, President, and Joan O. Weiss, Director, Alliance of Genetic Support Groups, Chevy Chase, Maryland, 1 800 336-GENE)

PRINCIPLE 2

Family/Professional Collaboration Recognizes and Respects the Knowledge, Skills and Experience that Families and Professionals Bring to the Relationship

Families and professionals bring essential knowledge, skills, and experience to a collaborative relationship. In the past, families were often considered the receivers of professional expertise, without acknowledgement of the unique and valuable contribution they make. The collaborative model recognizes the expertise of all the people involved in caring for a child with special health needs.

Professionals and consumers can often both be considered experts. In genetics, as in many other fields, a consumer's life experience and knowledge are essential to making good use of the scientific information and clinical experience of the professional. Now more than ever, there is a need to foster a partnership between professionals and consumers and break down barriers to communication.

(J. Mackta, Parent)

With their knowledge regarding certain aspects of a child's condition, professionals at times may lose sight of the fact that the family is the center and the constant in the child's world, whereas professionals move in and out of the various service systems. The family is intimately familiar with the strengths and abilities of the child, the challenges of providing care and the needs of others in the family. This knowledge is critical to the success of any health care plan.

For a number of years, the attitudes of professionals working with families have seemed to say, "Tell us what your problem is and we'll fix it." The professionals were in a sense in control. We professionals need to change our orientation. We need to reframe that question to ask simply "How can we help you?" We need to begin to view our work with families as a partnership in which we are the consultants but the families are in charge, and it is on the care of their child that we are in fact consulting them.

(K. Barnard, Professional)

Each member of the team, family member or professional, brings an expert body of knowledge, skills, and experience to the relationship. Whether in a team meeting, during a home visit, at a doctor's office, or in a school setting, everyone must be encouraged and have an opportunity to express opinions and work together. It is impossible to develop a plan that ensures the best services for the child and the family without participation from all members of the team.

Collaboration and being a part of it all has enabled us (and others) to model for our daughter Cassilly how to problem solve—that everyone's point of view needs to be listened to and respected—that her "solutions" are valued (and often have been the ones selected). I guess that she, in increasing ways as she got older, has had not only choices but she shared in the responsibility of ensuring the best results.

(J. Woll, Parent)

Building on the experience of families and professionals who have worked together on issues related to a specific child is an excellent basis for work in the program and policy arena.

Collaboration has proven to be an exciting and powerful model for effecting national policy. I think the direct, honest realism families share with federal agencies makes it imperative we respond. We cannot use bureaucratic gameplaying and regulatory barriers to avoid action. It may be as dramatic as a family who helps change policy by appealing to the U.S. President to waive regulations which prevent them from taking their child home from the hospital or as subtle as the quiet, effective presence of families on the Federal Interagency Coordinating Council.
(M. McPherson, Professional)

Such opportunities for collaboration to improve programs and policies exist at the community, state, and national levels. Families and professionals can pool their knowledge, skills, and experience to initiate changes that reflect a family-centered approach to services.

PRACTICE EXAMPLES

FAMILY

It was in July, 1991, that I asked to see my daughter Bridgett's records while she was being cared for on the Pediatric Unit. Permission denied! How was I expected to care for my daughter on the weekend without knowing in detail about her care the previous five days? Was her new antibiotic started? Had she stopped vomiting and if so, when? Was her food staying down better? Four months later, after a series of letters explaining the need for parents to have access to their child's records, the pediatric facility conducted a training, changed their policy and now encourage parents to read and write notes in their child's records. (Maureen Mitchell, Regional Coordinator, Vermont Parent to Parent, Pownal, Vermont, 802 823-5256)

GRANDPARENTS

Grandparents can lend a type of strength and support to family members that no other generation can, just through their own experience and wisdom.
(J. Ratner, PACER Center)

In an effort to reach an underserved population that also is challenged by the birth of a child with a disability, a Grandparent-to-Grandparent program is being piloted through the PACER Center. The program goals are to:

- allow grandparents of children with special needs to share their concerns, joy, and interests with other grandparents;
- teach grandparents helpful strategies to support their children and families while caring for themselves;
- inform grandparents about programs and services available for children with disabilities and families;
- support, inform, and empower grandparents in assisting their children and grandchildren.

Grandparents will be trained to lead the support group and will expand a phone-support network for other grandparents. The idea behind the program is to have grandparents serve as their own best resources. (Jamie Smith and Paula Goldberg, Co-Director, PACER Center, Inc., Minneapolis, Minnesota, 612 827-2966)

COMMUNITY AND HOSPITAL

The Family Center in Newington, Connecticut, is a unique example of family/professional collaboration in the delivery of family support services. The Family Center was established through a recognition by the Newington Children's Hospital staff and parents that professionals are often unable to provide adequate family support services, and parents who have used specialized health care and other services have unique knowledge and experience to offer families. The Center is funded through a local, private foundation and the Developmental Disabilities Council, and administered by representatives of the Family Coalition Board and representatives of the Newington Children's Hospital Staff. The hospital provides significant in-kind support to the project, including space, telephones, and secretarial/ administrative supports. It also provides access to families in need of support. The Family Center enhances the delivery of family-centered care, both on-site at the hospital and in the community. Staffed by families, the Family Center provides parent to parent support, information, advocacy, and training opportunities for families of children with special needs. (Molly Cole, Coordinator, The Family Center, Newington, Connecticut, 203 667-5288)

STATE PROGRAM

Pilot Parent Partnerships, a statewide family network in Arizona, was formed in 1979 to provide support and information for parents of children with disabilities. The initial efforts were strong family/ professional collaboration and continued to be so as the organization grew. We began with two parents working from their homes with 15 volunteers to a staff of 14 and well over 400 volunteers in 15 chapters throughout Arizona. Our greatest family/professional collaboration challenge came when we decided to write a federal grant. As families, we had a clear vision of what we wanted, but needed lots of help in putting the pieces together. It truly would never have happened without our professional colleagues who gave their time, energy, and expertise to help families build a strong network. (Mary Slaughter, Executive Director, Pilot Parent Partnerships, Phoenix, Arizona, 602 468-3001)

TRAINING PROGRAM

Project Copernicus: Promoting the Practice of Family-Centered Care believes that both preservice and inservice training can help professional service providers deliver their services in a more family-centered way and that training is most effective when parents are engaged as training partners. As consumers of services, parents and other family members are uniquely qualified to share insights, observations, and ideas that may not be readily apparent to staff. Parents can and should participate in every level of training: determining needs, designing programs, producing materials, conducting sessions, receiving training sessions, receiving and evaluating training. (Lisa Maddux, Project Coordinator, Project Copernicus, Baltimore, Maryland, 301 550-9700)

Family/Professional Collaboration Acknowledges that the Development of Trust is an Integral Part of a Collaborative Relationship

PRINCIPLE 3

Trust means to have a firm belief or confidence in the honesty, integrity, and reliability of one another. In collaborative relationships, families and professionals need to trust each other in order to meet the special health needs of the child. This trust validates each person's expertise and implies a shared belief that everyone is interested in providing the best services for the child and family.

Collaboration requires going beyond cooperation (being nice) and truly working together, in an atmosphere of mutual respect and trust. The climate must be one in which families and professionals feel comfortable honestly exchanging ideas, as well as candidly asking questions and sharing concerns.
(S. Dietrich, Professional)

It is important to remember that trust is something that develops over time. At an initial meeting, the groundwork is laid for a trusting relationship by promoting openness and willingness to discuss with one another, what each will bring to the relationship. As time goes on, this commitment to an honest dialogue fosters trust.

Soon after Elsie was born, it became clear that the Intensive Care Nursery staff were as emotionally invested in her outcome as we were. Clearly, we were unable to give her the technical help she needed at that time, and we weren't there all the time to hug and love her. We entrusted them with her care, emotional and physical, and I have no doubt that by the time she was discharged, they loved her as much as we did, I think the fact that we trusted them as they trusted us as new parents greatly enhanced the care Elsie received.
(M. Sutton, Parent)

A collaborative relationship is a trusting relationship where expectations, hopes, and sometimes dreams are shared. Trust does not require agreement on all issues, nor does trust require perfect solutions. When disagreements do occur, it is easier to resolve them within the context of a trusting relationship.

Trust is a delicate thing. For me, it is releasing my child and sharing my hopes with the professionals in our lives. It is believing that you are as my sister/brother, that as a professional you are using your judgment and heart to push for what you feel is best for my child, that we can disagree, that we respect each other's knowledge and can meet on middle ground.
(D. Sosa, Parent)

Trust strengthens a relationship. It signifies a willingness to have faith in each other's intentions and acknowledges shared goals. The relationship created while trust is developing helps families and professionals overcome barriers to effective services.

Our rocky path has been smoothed to a great extent by our family pediatrician. When we first met, I'm afraid what he saw was two wounded and frightened parents who resented the fact their children would be dependent on a medical system that thus far had been something of a disappointment . . . He offered no judgments on just what kind of parents he thought we would make and never has. He asked what our concerns were and what our goals were for our children. As simple as that may sound, no doctor had previously asked those questions, much less waited for an answer.

(S. Thorson, Parent)

Professionals have a special responsibility in the development of trust. They may be strangers to the family, yet they play an important role in meeting the health needs of the child. Additionally, since families may feel dependent on the services being provided, they may be hesitant to place themselves in a vulnerable position. Professionals who show genuine interest in the family's and child's well being, who are accessible, and who are committed to honest communication foster trusting relationships.

Many families view specialists as unapproachable and would never disagree or challenge statements made by one of them. We have found that, though we seem to get respect from these wonderful people automatically, we do not gain their trust as easily. . . .Some of the ways that our staff builds trust relationships are: accompanying the family when a referral has been made to an outside agency as part of the evaluation process, and serve as interpreter; keeping notebooks in each child's cubby so that family members and specialists may exchange dialogues on the work the child is accomplishing; assisting parents in filling out various documents; and encouraging parents to call us and let us know how their child is doing once he leaves our school and is enrolled in the public school system.

(L. Vaughan & I. Lorenzo-Hubert, Professionals)

Trust involves risk. For families, it means entrusting the care of their child to others in the belief that they will be sensitive to the family's goals and wishes. For professionals, it means that they may not meet the expectations of the child and family. For both families and professionals, it can mean exposing vulnerability. Trust must be earned. Once it is achieved, trust creates an atmosphere in which the dynamics of the relationship can flourish.

PRACTICE EXAMPLES

FAMILY

Our daughter Katie was born with medical conditions which required an extended hospital stay. When Katie was somewhat stable and no real progress in the hospital was being made, we were approached about taking Katie home. The doctors, nurses and therapists trusted us to handle and assess Katie's needs on a 24-hour basis. They recognized her need to be in a more normal and social atmosphere. However, Katie had no access to the home health care she would require without access to insurance. We requested that income eligibility limits be waived to establish Medicaid eligibility under the Supplemental Security Income Program. Although we were told "rules are rules," Medicaid did say that an exception to policy would be processed; however, no one had ever received one in the state of Iowa. With the help and support of our

community, we worked to change the regulations which prevented us from bringing Katie home. In collaboration with Congressman Tom Tauke's office, the hospital social service department, the business office, the PICU staff and our family we established a precedent that allowed Medicaid to follow Katie home. On December 19, 1981, Katie came home to live after three years in a Pediatric Intensive Care Unit. As the result of our efforts, new Federal Medicaid initiatives were developed which allowed cases to be evaluated on an individual basis. By April 1982, the Department of Health and Human Services, realizing the enormity of the cases filed, established three options for state Medicaid programs known as the Katie Beckett waivers. (Julie Beckett, Program Associate, CAPP Project, University of Iowa, Cedar Rapids, Iowa, 319 356-4294)

PROFESSIONAL

It can be difficult for medical professionals to support families especially when they choose nonconventional ways/approaches with children. I acknowledge and respect that parents have a right to make decisions about their children's care and that professional intervention is not necessarily a given. This idea can be challenging to the medical profession because we don't understand that a family may not choose to use all the services in the formal service network. I try to find out how this family has handled crisis in the past. Who helped them? Who were their supports? In some situations informal intervention may be more effective than the formal systems we have developed. (W. Carl Cooley, M.D., Dartmouth-Hitchcock Medical Center, Lebanon, New Hampshire, 603 650-7884)

STATE PROGRAM

I think the first tangible evidence we ever had that the system respected and trusted our ability to care for Meredith was with the Family Support Subsidy Program. They respected my need for as much simplicity as possible by making the application process easy, i.e., a one-page application form and clear-cut eligibility requirements. They acknowledged my need for multiple supports by making the funds non-taxable and excluding the funds from income when applying for any other program. Most importantly, though, they demonstrated trust in me as a well-informed and prudent judge of my family's needs by placing no constraints on how the money is used. It's up to us to simply cash the check and buy respite, diapers, prescriptions, equipment, clothing, or anything else our family needs. (Beverly McConnell, Director, Parent Participation Program, Department of Public Health, Lansing, Michigan, 315 256-3684)

ADOLESCENTS/HOSPITAL

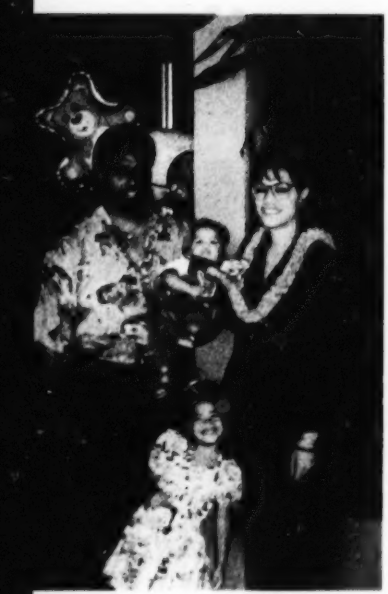
The objectives of the Family Autonomy Project are to: 1) ensure the participation of families in planning for the health care of their children, 2) modify staff behaviors and institutional practices to promote family autonomy, and 3) broaden service goals so that they include health maintenance and future planning for adolescents with special needs. Trust has been developing through participation between families and professionals on various committees, such as the staff-initiated Parent-Interest Committee which reviews and acts on parent and staff concerns at the Center. Parents have a direct impact on decision-making for all plans and activities at the Center. (Sharon L. Hostler, M.D., Project Director, Family Autonomy Project, Charlottesville, Virginia, 804 924-8174)

PRINCIPLE 4

Family/Professional Collaboration Facilitates Open Communication so that Families and Professionals Feel Free to Express Themselves

Communication, verbal and nonverbal, is the primary manner in which we relate to each other. Communication has an expressive aspect, such as talking, using a communication board, and signing—and a receptive aspect, such as listening, attending to the signs and signals, and understanding. For children with special health needs and their families and the professionals they work with, communication is the way we understand each other and share ideas and goals.

We as professionals must remember that it is the parents who know their child and who can tell us about the child. True, we may have technical knowledge about gross motor and fine motor development, but unless we can communicate with the parents and really know what is going on with the child, our recommendations may not be appropriate or may never be implemented because of miscommunication.
(E. Yamane, Professional)



Effective communication is the cornerstone of successful collaborative relationships.

Instrumental to increasing the family's ability to cope with the consequences of an illness or disability is open communication among members and between the family and health care personnel. Distorted, unclear, and disqualifying messages tend to generate confusion, tension, distance, and even alienation.
(K. Ell and H. Northen, Professionals)

In health care situations, the professional may wish to protect the child and/or family from pain or sadness, leading to a lack of openness in communication. While the professional may have good intentions, the family must have access to all available information about their child. Sometimes professionals do need to communicate painful information. In these situations, the decision is not whether to give the information to the family but rather how to give it.

I vividly remember the first time I met Elsa [a professional advisor to the Treacher Collins Foundation]. . . .her approach toward me then, as now, was warm and welcoming; she seemed unhurried, energetic, respectful, and honest toward my concerns. She displayed an uncanny ability to ask the right questions of me so that I could ask the right questions of her. I left our meeting feeling exuberant. . . .my perspective about my son's potential, his future, and that of our family changed dramatically during this conversation.
(H. Charkins, Parent)

Collaborative relationships are characterized by dialogue—an ongoing effort by all persons to discuss the issues and concerns at hand, to exchange information, provide feedback, share reactions and ideas, and create solutions. If the family's first language is not English, this dialogue should be conducted in a manner that makes it easy for families to express themselves.

With the Latino culture that I work with, much importance is placed on a person's capacity to observe his/her environment. That capacity goes beyond the words a person speaks and takes into account body language and presence. It is important for the professional working with Latinos to understand the way we interact with the environment, that even when the family does not speak the same language, their culture and heritage have prepared them with other ways of receiving information by the messages professionals send to them. It is on the basis of that information that the parents will develop their judgment on the quality of care their children are receiving.

(C. Santiago, Professional)

Central to developing a dialogue is listening. Active listening—checking out with others your interpretation of their statements and listening beyond words to hear and understand concerns — is hard work.

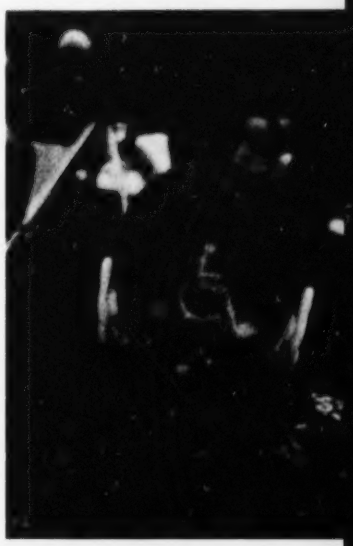
And when we shared our story, he listened—he really listened. No interruptions to be summarizing our feelings or using touchy, feely comments. He just listened...he also asked to see David, asked about him by name; I remember us standing around the crib and how we all talked about David as a person and not necessarily just about his special needs.

(P. Nishimoto, Parent)

Sometimes professionals feel that they are communicating with families and giving them information. But, in reality, the exchange is one-sided and ineffective. There also may be times when families are not clear in their communications with professionals, for example, in the areas of preferences for services or support. Developing a relationship which facilitates clear and open communication is crucial to the collaboration needed to fulfill child and family goals.

Now when I think back, many of the things I said and did were not smooth, nor was I learned or smart. I made mistakes. But it was my authentic sense of outrage or frustration that did carry the impact, clumsy or not. I am thankful to the professionals who listened, who heard beyond the lack of correctness and style, and appreciated the message. My remarks did make a difference. I know this because professionals would say to me, even years later, that they were somehow moved to action by them.

(J. Vohs, Parent)



PRACTICE EXAMPLES

FAMILY

We had wonderful modeling of a great communication approach when my son was young. Our neurologist would meet with us all together and then near the end would say, "Now Michael, I want to talk with your parents alone for a few minutes and then with you alone." There were a number of worrisome things happening neurologically at that time and we had questions and concerns that we as parents wanted to clarify before talking about them with Michael. . . . it also took into account that Michael himself might have some personal questions. . . .and would be a particularly good approach as children grow to assume their own care. (Betsy Anderson, Director, CAPP, National Parent Resource Center, Federation for Children with Special Needs, Boston, Massachusetts, 617 482-2915)

SISTERS AND BROTHERS

The goal of the Sibling Support Project is to increase the number of peer support and education programs throughout the United States. One of its activities has been the development of the Sibshop Model which offers brothers and sisters of children with special health care needs opportunities:

- to meet other siblings in a relaxed recreational setting;
- to discuss common joys and concerns with other siblings;
- to learn how others handle situations commonly experienced by siblings of children with special needs; and
- to learn more about the implications of their brothers' and sisters' special needs.

They also provide parents with an opportunity to learn more about common concerns of brothers and sisters. (Donald Meyer, Project Director, Sibling Support Project, Children's Hospital and Medical Center, Seattle, Washington, 206 368-4911)

SCHOOL

Longview School in central Phoenix, Arizona, has a large percentage of Hispanic students. The staff of the school make a strong effort to meet the needs of these students and their families. In the area of health and medical needs, the school nurse and the home-school liaison, who are Spanish-speaking, are available to help families with children with special health care needs: access medical evaluations, to work with teachers to make classroom modifications, and to connect parents to parent organizations with Spanish-speaking support parents. (Eduarda Rosh, R.N., School Nurse, Longview School, Phoenix, Arizona, 602 264-2665)

TRAINING

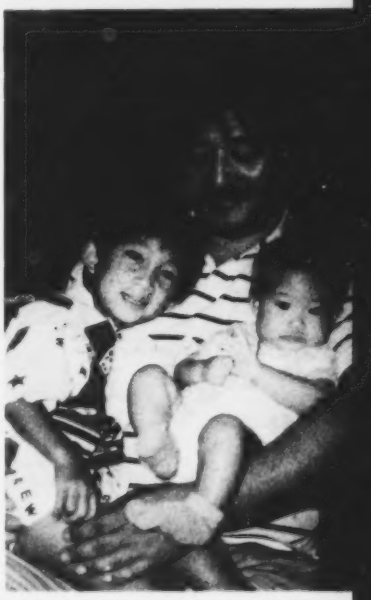
Medical Education Projects, Hawaii, New Mexico, Vermont, Wisconsin. As part of an effort to develop a dialogue between parents and physicians concerning quality health care for children with special health needs, medical students in pediatrics are invited to spend time in the homes of families who have children with special health needs, listening and learning about the child within the context of the family. Medical students are not meeting with families as expert physicians, but rather to understand the knowledge, skills, and values that families bring to the family/professional relationship. Other activities may include lectures and discussions between families and professionals within the medical school setting. Hawaii, New Mexico, Vermont, and Wisconsin are examples of states with medical education projects. (Consult the Family/Professional Collaboration Resource List on page 43 for contact persons.)

STATE PROGRAM

A local government project begun in 1983 in Texas, established the Community Information Services (CIS). The State Department of Human Resources' Houston office worked with the Houston Public Library system to develop a model information service. Now funded by United Way, the United Way Helpline uses a computer-based data bank to answer telephone inquires about information and services. Telephone lines maintained by the United Way are staffed by bilingual workers who have received special training. (Pam Perez, United Way Helpline, Houston, Texas, 713 957-4357)

Family/Professional Collaboration Creates an Atmosphere in Which the Cultural Traditions, Values, and Diversity of Families are Acknowledged and Honored

PRINCIPLE 5



Families of children with special health needs are represented among the great variety of cultures in our country. Many families face the added challenge of dealing with systems which may not understand or support their language, beliefs, traditions, or ways of life.

Each family is unique and self-defining, an exotic culture with a language, a style, and rhythm unlike any other's.
(J. Freeman, Professional)

One of the greatest challenges faced by families and the professionals they collaborate with is to understand each other: why we talk as we do; why we behave in a certain manner; how we make decisions; how each of us views children in general and children with special health needs in particular; how past experiences and cultural traditions affect the thinking and actions around a child's health care. This does not mean to intrude on the family's privacy. Nor does it imply that a professional should ask too many questions about family life. Instead, it means that an atmosphere is created in which the family is respected for who they are and for their commitment to their child.

In spite of the problems with the language, one has to ask questions. It was very difficult for me in the beginning, but the people at the hospital really helped, and I know that I helped them too. I go to the appointments because they take me seriously when I speak about my children's conditions.
(L. Dávila, Parent)

What does it mean to have collaborative relationships which are sensitive to and honor the diverse backgrounds of families from different cultures? According to Cross (1988), sound cross-cultural practice includes five essential elements: an awareness and acceptance of difference, an awareness of the influence of the professional's culture on how she or he thinks and acts, an understanding of the dynamics of difference in the helping process, knowledge of the family's culture, and the ability to adapt practice skills to fit the family's cultural context. This work on honoring diversity through cross-cultural practice is an important responsibility for professionals, and is a process that is continuous and occurs over a lifetime.

Acceptance of the fact that each culture finds some behaviors, interactions or values more important or desirable than others can help [professionals] interact more successfully with members of different cultures. Awareness and acceptance of differences in communication, life view and definitions of health and family are critical to successful outcomes.
(J.S. Gallegos, Professional)

Families who are caring for a child with special health needs often find themselves drawing on their cultural heritage for comfort and as a means of finding their way. These familiar courtesies and traditions can become starting, resting, or decision-making safe havens. If professionals are able to demonstrate to the family a willingness to be respectful, families will show professionals how to provide services and support in a way that is acceptable and meets the family's needs.

When a serious decision must be made, we talk it through with extended family members or listen to our elders. Then, together we decide what is best for the child. Some doctors get upset with us if we do not make an immediate decision on the treatment they recommend for our child. But others respect our cultural way of making decisions. They invite family members to take part in the discussion and give us time to decide what makes it much easier for us. Our traditional ways are important to us, and we respect them.
(American Indian Parent Group)

Creating an atmosphere in which the cultural traditions, values, and diversity of families are acknowledged and honored goes beyond the practice level. Professionals need administrative support to collaborate in culturally sensitive ways. Some examples of this administrative support include hiring practices which include people of diverse ethnic groups, access to special communication techniques, and staff training by families and professionals representative of the various cultures being served.

Developing collaborative relationships with families is a way of helping all families gain access to services. This is especially significant in working with families from various cultures. This means, among other things, having professionals who speak the first language of the family, meeting in a place which is comfortable for family members, and learning the particular customs that are a part of the family's culture.

I have always been a strong believer in the importance of outreach for many reasons. I think outreach such as meeting in people's homes, certainly can contribute to a collaborative relationship. I'm not saying you have to go to someone's home to collaborate, but I am saying that reaching out and asking how a family wants to work with me is a way to understand better the family's experience, and journey.
(P. Weaver, Professional)

PRACTICE EXAMPLES

FAMILY

After two years of being home with my son, I'd reached my limit. I knew he would be entering the public school system soon, but I needed time now as well as a foolproof transition process from the early intervention program to special education for both of us. I requested that the two transition specialists from my son's program go with me to meet the director of the child development center in our community. They met me at my home and walked to the program with my son and me. We talked with the director as a team, they helped me articulate my thoughts. They even took turns taking care of my son while we were there so that I would not be distracted. Last, but not least, they made themselves available should the center need further information to better mainstream him into a program with no child diagnosed with any special health care need or disability. We were a team working for the benefit of my family. They supported me throughout the entire enrollment process. They were my partners, they are my friends. (Gail Johnson, Parent Network Coordinator, National Center for Family Centered Care, Bethesda, Maryland, 301 654-6549)

PROFESSIONAL

When I work with families I treat each person with dignity and respect. For instance, when I am called by a hospital to translate information to a family, the first thing I do is to speak with the family, explain my role, and ask their permission to translate, knowing that I will be hearing confidential information. Oftentimes hospital staff do not see this as an important step. I try to role model the importance of respecting the family, and taking the time to explain the family's right to confidentiality. (Carlos Santiago, M.S.W., Department of Public Health, Northampton, Massachusetts, 413 586-7525)

COMMUNITY PROJECT

The Southeast Asian Developmental Disabilities Prevention Project (SEADD) began out of a concern for the needs of newly-arrived immigrant families from Southeast Asia settling in the San Diego County area whose children were at risk for or who had developmental disabilities (ages birth-3). There are four immigrant groups served by SEADD, each of which has its own language, culture, and distinct issues. These include Cambodian, Vietnamese, Hmong, and Laotian families. The program employs four bicultural/bilingual case managers who were trained in the project and are from the same community that they serve. The receptionist/secretary speaks enough of each of the four languages so that she is able to greet families when they call and refer them to the appropriate case manager. Each of the case managers is an immigrant and has experienced the same hardships of refugee camps and dislocation/allocation as families in the program. The case managers help bridge the gap between the services families need and the network of services that are available to them in the community. (James O. Cleveland, Ed.D., Director, SEADD, San Diego, California, 619 576-2965)

STATE PROGRAM

To help improve the statewide systems of care for American Indian children with special needs, Southwest Communication Resources, Inc., a community-based agency, sponsored a conference to stimulate dialogue between American Indian parents and professionals providing services to Indian children. Participants were divided into three work groups, each having an equal mix of Indian parents and professionals and addressed the following topics: How can Indian parents and service providers work together productively and comfortably? How can early intervention services be provided to Indian families in a culturally appropriate fashion? How can Indian families be assisted in order to access the wide range of services for their children? Informally, all participants reported an increased understanding and appreciation of the issues. Participant recommendations included increasing Indian parent representation at all phases of planning; establishing a program of ongoing training for American Indian parents and advocates; orientation and on-the-job training on how to provide culturally responsive services; developing family service plans that are family-focused and culturally responsive; improving coordination among local, state and federal agencies serving American Indian children with special needs. (Randi S. Malach, Trish Thomas, Pathways to Understanding Project, Southwest Communication Resources, Inc., Bernalillo, New Mexico, 505 867-3396)

6 Family/Professional Collaboration Recognizes that Negotiation is Essential in a Collaborative Relationship

Why is the ability to negotiate suggested as an essential component of a collaborative relationship? In some ways, all relationships involve a series of negotiations. In the process of achieving the best and most family-centered services for children with special health needs and families, it seems inevitable that disagreements will arise—between family and professional, between professional and professional, and perhaps among family members themselves. When disagreements occur, then negotiation must take place—equals negotiating with equals!

As a parent, I need to feel from you that my child's life is as important to you as it is to me. That you value and cherish his individuality. That you are willing at times to stand back so that his wings may spread or at other times to come and encircle him. But to always remember the possibilities and the hopes that are in his eyes and in my heart. That you may not always agree, but we will work it out.

(D. Sosa, Parent)

Negotiation is a process of laying on the table the different options, priorities, and preferences of all team members. It means developing a plan to meet the needs of the child and family. The goal of negotiating is always to find the best solutions for children and families. Flexibility is essential.

In my son's life, our team of family and professionals is a critical factor in providing the support which allows Joshua to live and function in his community. As a team we have not always agreed but, because we have learned to trust and respect each other's expertise, we are usually able to reach consensus.

(K. Witkin, Parent)

According to Pinderhughes (1989), mediating and resolving conflict can be critical in preserving relationships and preventing relationship breakdown and isolation. In mediation, work is directed toward the best outcomes for the child, not on the differences between and among individuals. Empowerment efforts are directed toward the relationship rather than toward any one individual.

My son's physician is great! We work together to meet my son's needs. If we are not sure how to proceed on an issue, I might say: "Why not try this." And he listens to me!

(L. Lemons, Parent)

Negotiation and compromise can be seen as activities that encourage growth. Over time, issues may need to be negotiated more than once. These new negotiations may result from a number of factors including the changing needs and wishes of the child and family, new information, new and changing resources in the agencies, and new technologies.

We [professionals] need to realize that we are not going to be able to have one approach or one program or one set of parent meetings that fits every parent. We're not going to be able to demand that they meet those kinds of expectations.
(L. Vincent, Professional)

Simple negotiations may involve more concrete issues such as times, places, and dates for meetings. More complex negotiations may involve the resolution of differences of opinion over more serious challenges in service delivery, such as disagreements over the need for medications, the number of respite hours needed, and professional style of service delivery. The ability to negotiate is crucial to collaboration.

Collaboration is also necessary because among other reasons neither the parent nor the professional possesses a monopoly on the truth, and each can serve as a check on the shortcomings and limitations of the other. But before a partnership can genuinely exist, there must be give-and-take, mutual respect, and something like moral and cultural equality. Both the parent and the professional must attempt to understand the other's point of view, special moral concerns, and culturally determined priorities of the child.
(J. Gleidman and W. Roth, Professionals)

PRACTICE EXAMPLES

FAMILY

Our son Mark had multiple orthopedic surgeries throughout his life, involving much collaboration among various professionals and our family. The greatest challenge to these collaborative efforts came when Mark needed another surgery after turning the magical "legal" age of 18. Not only were we transitioning from pediatrics to an adult health care system, but Mark was now the legally responsible party. He signed all consent forms, negotiated with health care providers, and made his own decisions about anesthesia induction, pain management, etc. It was a new experience for my husband and me, letting go of control, but for the health care team who also needed to make adjustments. Mark became one of the collaborators, with support from his family, and the professionals took another step toward partnership. (Betsy Trombino, Program Director, Pilot Parent Partnerships, Phoenix, Arizona, 602 468-3001)

FAMILY, SCHOOL AND COMMUNITY

Negotiating for services in a rural community in Mississippi involved networking parents at the local level to communicate the needs of their children to educators in the local school district. This negotiation began with parents discussing the needs of their children. These needs were taken to the program developer of the local school district. Within two weeks of communicating with the program developer, children who had been traveling eighty miles one way for education and therapy began receiving services in their community. The development of these services in Benton County, Mississippi resulted in awareness in the community and improved communication and collaboration among parents and professionals. Negotiation doesn't end with the development of services. Any

change in services requires negotiation. Therefore, communication and collaboration cannot be overemphasized. Always remember—just because someone says no doesn't mean it can't be done. Persistent negotiation utilizing factual information and positive advocacy can bring about not only services, but a good working relationship for continuing and improving services. (Kathy Tullos, Executive Director, Advocates for the Exceptional, 601 656-9345, Philadelphia, Mississippi, and Linda Lemons, currently in Memphis, Tennessee, 901 353-2019)

EARLY INTERVENTION PROGRAM

At the Sultan School this year we offered limited home-based services on a pilot basis. However, we also explained to the families the amount of time we had available to provide these services. We wanted families to help us determine the effectiveness of the pilot—in terms of quantity, quality, and need. The results from this small experiment in negotiation and compromise has shown us that families (1) are willing and eager to participate in improving and expanding the program and that they are conscious of cost-effectiveness; (2) are able to articulate an overriding preference for continuity of services rather than site of services; and (3) are partners in trying to figure out the best way to use the dollars we had. (John Nishimoto, Sultan Easter Seals School, Honolulu, Hawaii, 808 536-3764)

STATE PROGRAM

In 1991, the Vermont Department of Health's Division for Children with Special Health Needs (CSHN) undertook the task of reorganizing the way families would purchase prescription drugs for their children. The group which planned the changes was the State Advisory Council for CSHN whose co-chairs and membership are parents and professionals. Additionally, the parent members were asked to seek ideas and concerns from families around the state. The resulting new prescription drug policy represents an important collaborative effort between a state administrator, parent groups, individual families, and providers. It reflects a program that is most responsive and least disruptive to children and families while still adhering to cost-effectiveness. (Carol Hassler, M.D., Director, Division for Children with Special Health Needs, Vermont Department of Health, Burlington, Vermont, 802 863-7338)

Family/Professional Collaboration Brings to the Relationship the Mutual Commitment of Families, Professionals, and Communities to Meet the Needs of Children with Special Health Needs and Their Families

PRINCIPLE 7

Families live in communities. That's where parents work, where children go to school, and where the family attends religious services. Community is a place where we look for support and services.

It takes a community to raise a child.
(African proverb)

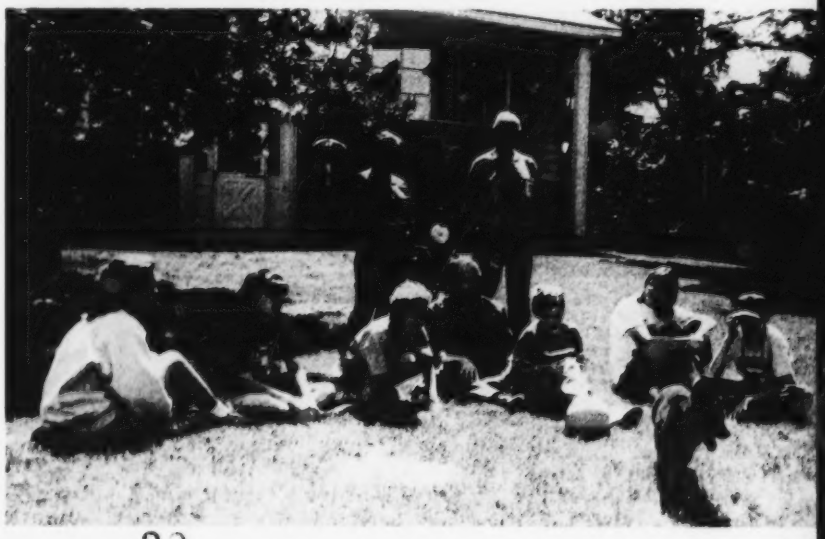
While a great deal of attention has been paid to the need for and importance of a commitment from families and professionals to children with special health needs and their families, there has been less focus on the need for a commitment from communities. According to Hobbs, Perrin and Ireys (1985), community is "the shared commitment of a group of people to mutual assistance and the achievement of common purposes."

Our doctor initiated involvement with the early intervention team and later the preschool program. At his request, we have invited him to IEP meetings. He contributes information regarding the boys' medical problems, a perspective often forgotten by educators. And his presence alone sends a message that not only do these parents have a commitment to the development of their children, so does their doctor, and so does this community.
(S. Thorson, Parent)

Community can be a neighborhood, a village, a town, a part of a city, or a city. Community implies mutual caring, common benefits, a shared vision. Families can care for their children with special health needs more effectively and with less stress and frustration if they are supported by their community of neighbors.

Community implies sharing the responsibility to ensure that children with special health needs are included in all aspects of community life.

We must continue to work at changing attitudes through our own examples. . . .Everyone, no matter what color, shape, size or disposition, is special. In the words of Sarah Lightfoot, "If we would let individual gifts thrive, there would be more possibility for a rich community life."
(S. Peters, Professional)



A community commitment can be achieved through the inclusion of children with special health needs in many community activities and organizations including scout groups, preschool and daycare centers, religious events, and recreation programs.

A key strategy for strengthening community support is to increase public awareness of: 1) the developmental needs of children, 2) the specific needs of children with chronic illness or disability and their families, and 3) the mutual rewards of integrating every child and family into community life.
(New England SERVE)

In fact, children with special health needs can be full participants in all informal and formal neighborhood activities. In order to achieve the inclusion of children with special health needs in the community, parents, health professionals, educators, friends, neighbors, and others must see that appropriate supports—a ramp at the recreation center, interpreters at the high school play, a buddy system in the summer playground program—are available. This commitment by communities will assure collaboration among all the partners who need to work for children with special health needs and their families.

At this time, we will celebrate the newborn children in our community. As a community, we recognize that these beautiful children are the seeds of our heritage, fruits of our labor, and the future of our people. We must care for them, we must protect them, we must educate them, and we must love them. As a community, we must share these responsibilities.
(Ghanian "Adinto" Ceremony)

PRACTICE EXAMPLES

FAMILY AND COMMUNITY

Moving to a new community was unsettling for me and my two sons, especially moving from a small rural community to the city. But this move was to be a very pleasant experience. After four days, we had gotten to know almost everyone on our street. The kids were coming to the house to play with Shawn and Jason. They would go outside with them and race their wheelchairs. When I was settled in and ready to start my new job, the neighbors' children would come to my house and stay with the boys until their school bus arrived. In the afternoon, the teenagers would take turns about keeping the boys until I got home at 4:30. I feel this help and understanding came easily because when questions were asked, answers were given. The neighbors felt they could ask questions about the boys without feeling awkward or offending us. This open communication and sharing information resulted in support for my family and a willingness of the community to help. With no family in Jackson, the neighborhood soon became our family. (Kathy Pounds, Mississippi Parents and Families Network, Jackson, Mississippi, 1 800 779-8948)

FAMILY AND SCHOOL COMMUNITY

When the time came for Nick to go to kindergarten, we were strongly urged to take him to town (Albuquerque) where the special education services were supposed to be better. But our other kids had all gone to the little school in the village and our family just felt, by instinct, that Nick belonged here, in Algodones, where his brother and sisters and friends and neighbors were. It's a decision none of us has regretted. Even if he was the first child to go to the school in a wheelchair, he did fine. And

everyone benefited from Nick's presence. (Polly Arango, Co-founder, Parents Reaching Out, Algodones, New Mexico 505 867-3660)

COMMUNITY PROGRAM

The mission of the Brooklyn Pediatric AIDS Demonstration Project is to address the needs of children with the HIV infection, and their families. Family members may often include extended family and foster care parents. The goals of this project are to: 1) promote communication among pediatric health care and service providers and coordinate and expand medical, educational, developmental, and social services for an increasing population of infants and children with or at risk for HIV infection and their families; 2) identify infants, children, and adolescents with or at risk for HIV infection and their families, in order to provide appropriate assessment, medical management, and access to treatment as it becomes necessary; and 3) provide case management and social services in order to stabilize and support families with or at risk for having children with the HIV infection. Family members participate on all committees that address the above goals, and quarterly luncheons are held to invite families to provide input regarding services and project goals. (Sheri Saltzberg, Associate Director, Brooklyn Pediatrics AIDS Demonstration Project, Brooklyn, New York, 718 270-1828)

INTERAGENCY/COMMUNITY

Family First is an interagency child and family focused screening project for all newborns and their families living in the Lakes Region of New Hampshire. Family First has been funded by the New Hampshire Infant and Toddler Project under Part H of the Individuals with Disabilities Education Act (IDEA). The project's goal is to pilot an early detection model which links families with needed community supports and resources. Parents are offered the opportunity to participate in an ongoing and systematic process of screening and assessment in order to receive appropriate and responsive referral information. Family First offers a community based solution to federally mandated child identification activities as well as positive connections to child health, early intervention, early childhood education, and family support programs. (Karen Rockhold, Young Family Support Program Manager, Community Health & Hospice, Laconia, New Hampshire, 603 524-8444)

Family/Professional Collaboration: People and Programs

NATIONAL ADVISORY BOARD

Betsy Anderson
Director, CAPP, National Parent Resource Center
Federation for Children with Special Needs
95 Berkeley Street
Boston, Massachusetts 02116
(617) 482-2915

Polly Arango
Co-Founder, Parents Reaching Out
P.O. Box 338
Algodones, New Mexico 87001
(505) 867-3660

Nancy DiVenere
Director, Parent to Parent of Vermont
#69 Champlain Mill
One Main Street
Winooski, Vermont 05404
(802) 655-5290

Isadora Hare, A.C.S.W.
Staff Director, Commission on Education
National Association of Social Workers
750 First Street, N.E.
Washington, D.C. 20002-4241
(202) 408-8600

Carol Hassler, M.D.
Director, Division for Children with Special Health Needs
Vermont Department of Health
1193 North Avenue
Burlington, Vermont 05402
(802) 863-7338

Barbara Steele, M.S.W., L.C.S.W.
Resource Specialist, Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, Maryland 20814
(301) 654-6549

Joan O. Weiss, M.S.W.
Director, Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, Maryland 20815
(800) 336-GENE

Josie Woll
Director, Infant Program
Sultan Easter Seals School
378 Mamaki Street
Honolulu, Hawaii 96821
(808) 536-3764

FOCUS GROUP

Cathy Crow, Parent
103 Sugar Tree Lane
South Burlington, Vermont 05403
(802) 865-4918

Nancy DiVenere, Parent
Director, Parent to Parent of Vermont
#69 Champlain Mill
One Main Street
Winooski, Vermont 05404
(802) 655-5290

Carol Hassler, M.D.
Director, Division for Children with Special Health Needs
Vermont Department of Health
1193 North Avenue
Burlington, Vermont 05402
(802) 863-7338

Cindy Hayman, M.S.W.
Child Development Clinic
56 Colchester Avenue
Burlington, Vermont 05401
(802) 863-7315

Michele O'Neill, M.S.W.
Division for Children with Special Health Needs
Vermont Department of Health
1193 North Avenue
Burlington, Vermont 05402
(802) 863-7338

Susan Rump, Parent
P.O. Box 174
Thetford Center, Vermont 05075
(802) 785-4029

Carlos Santiago, M.S.W.
Family Health and Community Services
Massachusetts Department of Health
23 Service Center
Northampton, Massachusetts 01060
(413) 586-7525

Evelyn Sikorski, M.S.W.
Social Services Department
Medical Center Hospital of Vermont
Burlington, Vermont 05401
(802) 656-3553

Megan Sutton, Parent
R.D. #1
Middlebury, Vermont 05753
(802) 545-2475

Janet Vohs, Parent
Editor, Coalition Quarterly
Federation for Children with Special Needs
CAPP, National Parent Resource Center
95 Berkeley Street
Boston, Massachusetts 02116
(617) 482-2915

RESOURCES

Betsy Anderson
Director, CAPP, National Parent Resource Center
Federation for Children with Special Needs
95 Berkeley Street
Boston, Massachusetts 02116
(617) 482-2915

Polly Arango
Co-Founder, Parents Reaching Out
P.O. Box 338
Algodones, New Mexico 87001
(505) 867-3660

Julie Beckett
Program Associate
CAPP, National Parent Resource Center
239 Hospital School
University of Iowa
Iowa City, Iowa 52242-1011
(319) 356-4294

Hope Charkins
Treacher Collins Foundation
P.O. Box 683
Norwich, Vermont 05055
(802) 649-3020

James O. Cleveland, Ed.D.
Director, SEADD, San Diego Imperial Counties Developmental Services, Inc.
4355 Russin Road, Suite 205
San Diego, California 92123
(619) 576-2965

Molly Cole
Coordinator, The Family Center
Newington Children's Hospital
181 East Cedar Street
Newington, Connecticut 06111
(203) 667-5288

W. Carl Cooley, M.D.
Associate Director of Clinical Services
Dartmouth Center for Genetics and Child Development
Dartmouth-Hitchcock Medical Center
Lebanon, New Hampshire 03756
(603) 650-7884

Leticia Dávila
22 Barrett Avenue
Holyoke, Massachusetts 01040
(413) 536-5217

Nancy DiVenere
Director, Parent to Parent of Vermont
#69 Champlain Mill
One Main Street
Winooski, Vermont 05404
(802) 655-5290

Sharon Dietrich, M.S.W.
Family & Neighborhood Services
19101 Inkster Road
Romulus, Michigan 48174
(313) 941-9590

Susan G. Epstein, M.S.W.
Ann B. Taylor, Ed.D.
New England SERVE
101 Tremont Street, Room 615
Boston, Massachusetts 02108
(617) 574-9493

Barbara J. Friesen, Ph.D.
Center Director, Research and Training Center
Portland State University
P.O. Box 751
Portland, Oregon 97207-0751
(800) 628-1696
(503) 725-4040

Paula Goldberg
Co-director, PACER Center, Inc.
Jamie Smith
Grandparent Program
4826 Chicago Avenue, South
Minneapolis, Minnesota 55417-1098
(612) 827-2966

Stanley Handmaker, M.D., Ph.D.
University Affiliated Program
University of New Mexico
School of Medicine
Albuquerque, New Mexico 87131
(505) 272-3000.

Carol Hassler, M.D.
Director, Division for Children with Special Health Needs
Vermont Health Department
1193 North Avenue
Burlington, Vermont 05402
(802) 863-7338

Sharon L. Hostler, M.D.
Project Director, Family Autonomy Project
Children's Rehabilitation Center
2270 Ivy Road
Charlottesville, Virginia 22901
(804) 924-8174

Gail Johnson
Parent Network Coordinator
National Center for Family-Centered Care
Association for the Care of Children's Health
7910 Woodmont Avenue, Suite 300
Bethesda, Maryland 20814
(301) 654-6549

Michele S. Kern, R.N.
Program Administrator
Children's Medical Services
Department of Health & Rehabilitative Services
1317 Winewood Boulevard
Tallahassee, Florida 32399-0700
(904) 488-5040

Carla Lawson
Executive Director, Iowa Pilot Parents Inc.
33 North 12th Street
P.O. Box 1151
Fort Dodge, Iowa 50501
(515) 576-5870

Linda Lemons
Parent Coordinator, Family Support Group–Project Sunshine
Lebonheur Hospital
845 Adams Street
Memphis, Tennessee 38127
(901) 353-9481

Isabella Lorenzo-Hubert, M.Ed.
Laura Vaughan, M.Ed., CCC-SLP
Un Buen Comienzo Program
2000 Rosemount Avenue, N.W.
Washington, D.C. 20010
(202) 265-9885

Jayne Mackta
President, Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, Maryland 20815
(800) 336-GENE

Lisa Maddux
Project Coordinator, Project Copernicus
2911 Biddle Street
Baltimore, Maryland 21213
(301) 550-9700

Beverly McConnell
Director, Parent Participation Program
Children's Special Health Care Services
Department of Public Health
343 N. Logan/Martin L. King Jr. Blvd.
P.O. Box 30195
Lansing, Michigan
(315) 256-3684

Merle McPherson, M.D.
Director, Division of Services for Children with Special Health Needs
Maternal and Child Health Bureau
Parklawn Building, Room 18A-27
5600 Fishers Lane
Rockville, Maryland 20857
(301) 443-2350

Donald Meyer
Project Director, Sibling Support Project
Children's Hospital & Medical Center
4800 Sandpoint Way, N.E.
Seattle, Washington 98105
(206) 368-4911

Maureen Mitchell
Regional Coordinator
Parent to Parent of Vermont
RD 1, Box 296
Pownal, Vermont 05261
(802) 823-5256

John Nishimoto
Sultan Easter Seals School
378 Mamaki Street
Honolulu, Hawaii 96821
(808) 536-3764

Patricia Nishimoto, M.S.W.
Zero to Three Project
Family Health Services Division
Hawaii Department of Health, CSHN Branch
1600 Kapiolani Boulevard, Suite 401
Honolulu, Hawaii 96814
(808) 957-0066

Beverly Njuguna, M.S.W., J.D.
Executive Director, Beethoven Project
Center for Successful Child Development
4848 South State Street, 2nd Floor
Chicago, Illinois 60609
(312) 373-8670

Donna Gore Olsen
Project Director
Indiana Parent Education Project
2107 E. 65th Street
Indianapolis, Indiana 46220
(317) 257-8683

Pam Perez
United Way Helpline
P.O. Box 924507
Houston, Texas 77292
(713) 957-4357

Susan Jeanne Peters, Ph.D.
Department of Counseling, Educational Psychology & Special Education
Room 333, Erikson Hall
Michigan State University
East Lansing, Michigan 48824
(517) 353-0637

Kathleen Pounds
Mississippi Parents and Families Network
425 Louisa Street
Pearl, Mississippi 39208
(601) 936-8948
(800) 779-8948

Florene Stewart Poyadue
C.E.O., Parents Helping Parents
Family Resource Center for Children with Special Needs
535 Race Street, Suite 140
San Jose, California 95126
(408) 288-5010

Karen Rockhold
Program Manager, Young Family Support
Community Health Agency and Hospice
Laconia, New Hampshire 03246
(603) 524-8444

Eduarda Rosh, R.N.
School Nurse, Longview School
Phoenix, Arizona, 85016
(602) 264-2665

Sheri Saltzberg
Associate Director, Pediatrics AIDS Project
SUNY-HSCB
450 Clarkson Avenue, Box 49
Brooklyn, New York 11203
(718) 270-3825/3826

Carlos Santiago, M.S.W.
Family Health and Community Services
Massachusetts Department of Health
23 Service Center
Northampton, Massachusetts 01060
(413) 586-7525

Mary Slaughter
Executive Director, Pilot Parent Partnerships
2150 E. Highland, Suite 105
Phoenix, Arizona 85016
(602) 468-3001

Deborah Sosa
Health Care Resource Specialist
Washington PAVE
12208 Pacific Highway, SW
Tacoma, Washington 98499
(206) 588-1741

Megan Sutton
Parent to Parent of Vermont
RD#1
Middlebury, Vermont 05753
(802) 545-2475

Trish Thomas
Training Coordinator
Randi S. Malach
Pathways Project Director
Pathways to Understanding Project
Southwest Communication Resources, Inc.
Bernalillo, New Mexico 87004
(505) 867-3396

Sarah Thorson
Minneapolis Interagency Early Intervention Committee
5234 32nd Avenue, South
Minneapolis, Minnesota 55417
(612) 729-4755

Betsy Trombino
Program Director, Pilot Parent Partnerships
2150 East Highland, Suite 105
Phoenix, Arizona 85016
(602) 468-3001

Kathy Tullos
Executive Director, Advocates for the Exceptional
580 East Main Street
Philadelphia, Mississippi
(601) 656-9345

Janet Vohs
Editor, Coalition Quarterly
National Parent Resource Center
Federation for Children with Special Needs
95 Berkeley Street
Boston, Massachusetts 02116
(617) 482-2915

Anne Wallace, M.S.W.
Addison County Counseling Services
89 Main Street
Middlebury, Vermont 05753
(802) 388-6751

Peggy Weaver, M.S.W.
Project Coordinator
Family/Professional Collaboration Project
Department of Social Work
University of Vermont
Burlington, Vermont 05405-0160
(802) 656-1156

Joan O. Weiss, M.S.W.
Director, Alliance of Genetic Support Groups
35 Wisconsin Circle, Suite 440
Chevy Chase, Maryland 20815
(800) 336-GENE

Nora Wells
Federation for Children with Special Needs
95 Berkeley Street
Boston, Massachusetts 02116
(617) 482-2915

Karen Witkin
Parent Coordinator
Family/Professional Collaboration Project
Department of Social Work
University of Vermont
Burlington, Vermont 05405-0160
(802) 656-1156

Josie Woll
Director, Infant Program
Sultan Easter Seals School
378 Mamaki Street
Honolulu, Hawaii 96821
(808) 536-3764

MEDICAL EDUCATION PROJECTS

Nancy DiVenere
David Stifler, M.D.
The Medical Education Project
Parent to Parent of Vermont
#69 Champlain Mill
One Main Street
Winooski, Vermont 05404
(802) 655-5290

Margo Peter, M.Ed.
The Medical Home Project
Hawaii Medical Association
1360 South Beretania
Honolulu, Hawaii 96814
(808) 536-7702

Stanley Handmaker, M.D., Ph.D.
Christy Barden, R.N.
New Mexico University Affiliated Program
School of Medicine
University of New Mexico
Albuquerque, New Mexico 87131
(505) 272-3000

William Schwab, M.D.
Associate Professor
Physician Education Project on Developmental Disabilities
University of Wisconsin
Department of Family Medicine and Practice
777 South Mills Street
Madison, Wisconsin 53715
(608) 263-7947

Family/Professional Collaboration: Suggested Readings and References

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Key Elements of Family-Centered Care

1. Recognizing that the family is the constant in the child's life, while the service systems and personnel within those systems fluctuates.

2. Facilitating parent/professional collaboration at all levels of health care: care of an individual child; program development, implementation, and evaluation: and policy formation.

3. Honoring the racial, ethnic, cultural, and socioeconomic diversity of families.

4. Recognizing family strengths and individuality and respecting different methods of coping.

5. Sharing with parents, on a continuing basis and in a supportive manner, complete and unbiased information.

6. Encouraging and facilitating family-to-family support and networking.

7. Understanding and incorporating the developmental needs of infants, children, and adolescents and their families into health care systems.

8. Implementing comprehensive policies and programs that provide emotional and financial support to meet the needs of families.

9. Designing accessible health care systems that are flexible, culturally competent, and responsive to family-identified needs.

Source: National Center for Family-Centered Care. (1990). *What* is *family-centered* care? (brochure). Bethesda, MD: Association for the Care of Children's Health.

For more information and resources about family-centered care policies, programs and practices, contact the Association for the Care of Children's Health (301-654-6549), 7910 Woodmont Ave., Suite 300, Bethesda, MD 20814.